

Manifesto

for people with rare and less common cancers

Cancer52 represents 80 predominantly cancer patient charities, united by their vision of seeing a better future for everyone affected by the rare and less common cancers - which are defined as all cancers outside the 'big four' of breast, prostate, lung and bowel. Our members represent patients affected by over 50 different cancers. These cancers differ: their mortality rates, their incidence and prevalence, the relevance of screening and levels of research into them.

Whilst we appreciate the difficulties facing the NHS we cannot ignore the rising proportion of cancer deaths due to less common cancers, up from 52% of all cancer deaths in England in 2006 when we were founded, to 54% in 2011ⁱ. We know tackling 'killer diseases', like cancer, is a 'key priority' for the Secretary of State and that his ambition is 'reducing our mortality rates for killer diseases from some of the highest in Europe to the lowest'. We want that priority reflected in a refreshed cancer strategy, in the NHS Outcomes Framework and the Strategy for Specialised Services in England.

We also want to see similar measures introduced in the other UK nations and referenced in the implementation plans for the UK Strategy for Rare Diseases. These must recognise that for some rare cancers a coordinated UK wide approach is necessary. We want:

1. Refreshed cancer strategies across the UK

We recognise all four nations have made progress in tackling cancer through their adoption of cancer strategies. We want all political parties to commit to refreshing their strategies and include extensive policies and programmes whose objectives are tailored to addressing the problems confronting the less common cancers patient population.

2. More research into the rare and less common cancers

Thanks to ongoing research effort, in which the UK plays a leading role and which some of our members fund, we know more about cancer. But research into less common cancers lags behind that for the big four cancers. That is echoed in the flagship 100,000 Genomes Project. This is not aligned with commitments made elsewhere that recognise the era of stratified medicines where small patient groups, often sub groups, are the focus. We want all political parties to ensure a place is found for all patient populations in the Genomes Project.

3. Early access to modern treatments and services

Early diagnosis and onward referral of cancer patients has been the key focus for tackling rising mortalities for the less common cancers. This is not enough if waiting times for treatments are growing and patients struggle to access effective treatments. In England, the uncertainties relating to Value Based Assessment and expiry of the Cancer Drugs Fund exacerbate this situation. Similar uncertainties prevail in the other nations. We want all parties to commit to decision-making where patient experience and their perspectives on what is 'worth it' involve patients rather than it being some cursory tick box exercise.

Find out more about us: www.cancer52.org.uk

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ⁱ 70,647 people died of a rare or less common cancer in 2011 and 132,770 people were diagnosed in 2012 Source Cascade, National Cancer Registration Service, Public Health England, accessed 21st May 2014)